

Fragile X Awareness Day Testimony

To: Members of the GAE committee
From: Jennifer Weitz
Subject: Fragile X Awareness Day
Date: 3/23/2009

Madame Chair/Mr. Chairman and members of the committee, my name is Jennifer Weitz, I live in Southbury and I would like to support bill S. B. No. 337. I urge the committee to please designate September 12 as Fragile X Awareness Day.

My seven year old daughter Jillian and my four year old son Jason were both diagnosed with Fragile X in September of 2006. Both of my children presented with significant developmental delays beginning at around 9 months of age, however, in spite of visiting countless pediatricians, neurologists, orthopedists, rehabilitative physicians, optometrists, geneticists, and therapists, we did not receive a diagnosis for many years. This is because no one knew about Fragile X. Even the geneticist was unable to pinpoint a correct diagnosis. We spent a significant amount of time and money and experienced quite a bit of emotional distress on our road to discovering an accurate diagnosis. Now that we have the diagnosis, we are able to gather the appropriate tools from the limited number of devoted doctors and researchers in the country who specialize in Fragile X. This, again, does not come without significant cost. We have traveled to Staten Island, Boston and California to meet with these rare and knowledgeable professionals. We have spent further resources flying these professional to Connecticut to help educate the schools and therapists who work with my children every day.

It is imperative that we raise awareness of Fragile X to help those who are already diagnosed get the correct treatment and to educate others so that they can be properly diagnosed. Please consider designating September 12 Fragile X Awareness Day to help our children and the many others out there who are undiagnosed.